Department of Veterans Affairs

Quality Enhancement Research Initiative (QUERI)

Spinal Cord Injury QUERI Center

Strategic Plan

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PART I: Center Mission, Goals and Scope

The central mission of Spinal Cord Injury (SCI)[1] QUERI is the promotion of patient health, functioning, and quality of life, through the implementation of evidence-based methods for enhancing patient self-management and disease prevention in the context of multidisciplinary care. In carrying out this mission our primary areas of focus have been respiratory health and pressure ulcers. However, SCI is not a discrete disease but rather, a life-long condition that impacts all domains of functioning, and influences the manifestation of many other diseases/conditions. Therefore, our interest is in developing implementation programs that have the most potential for generalizing across the numerous disease conditions that are important to veterans with SCI. In this spirit, SCI QUERI strives to develop multiple areas of research that converge on the underlying themes of enhancing patient self-management, promoting disease prevention, and building more effective interdisciplinary care. Finally, because we work so closely with VA's SCI/D services, we try to be responsive to critical, time-sensitive and emerging issues in which QUERI can have an impact. Therefore, while we continue to emphasize projects in the areas of respiratory health and pressure ulcers, we are exploring and advancing implementation projects related to obesity, pain and depression, physical function/mobility and cross-cutting issues such as the use of telehealth and MyHealtheVet in SCI. (See Figure 1: Pipeline).

I.1 Clinical Focus and Scope

Patient population. During World War I, 80% of individuals with a spinal cord injury (SCI) died within a few weeks of injury and more than 95% died within one year. Today, more than 90% of the individuals with a new SCI survive, to live for an average of more than 40 years after injury. One result of these remarkable increases in survival rates is the need is the need for a system of care that can help veterans with SCI/D adjust to a chronic condition requiring ongoing management of impairments, prevention of complications, and promotion of healthy aging.

SCI System of Care. The Veterans Health Administration (VHA) SCI/D system of care includes 23 regional SCI centers at primarily large to medium size VA facilities that provide comprehensive, coordinated lifelong care delivered by interdisciplinary teams. The SCI centers work with the remaining VA facilities, which includes 135 SCI primary care teams or outpatient

[1] *Please note that while the SCI QUERI addresses issues for persons with spinal cord injuries and disorders (SCI/D), much of the literature available is based on traumatic injury populations only. Thus, we use both SCI/D and SCI in this document to distinguish when references are specific to traumatic injuries.*

support clinics to facilitate efficient, coordinated, and appropriate delivery of care, referred to as the "hub and spokes" model. Through this system of care, a full range of services, including preventive, primary, specialty, emergency, sustaining, outpatient, home, long term, and end-of-life care is provided. SCI/D Services (formerly SCI Strategic Healthcare Group) is responsible for the oversight and national leadership in VA SC/D care. The Chief Consultant (Margaret Hammond, MD) and Associate Chief Consultant (Barry Goldstein, MD, PhD) for SCI/D Services are also the co-Clinical Coordinators of the SCI QUERI.

Clinical Conditions. Although veterans with SCI/D all share spinal cord dysfunction and neurological deficits in common, there are a multitude of co-morbidities that relate to alterations in somatic function (e.g., pain, spasticity, pressure ulcers), autonomic function (e.g., impaired cough, neurogenic bladder, autonomic dysreflexia), and inactivity from paralysis (e.g., obesity, diabetes, dyslipidemia). We continue to work on several high-risk, high volume, high-cost conditions (i.e., respiratory health, pressure ulcers, obesity, pain & depression), but are also attempting to address emerging issues such as OEF/OIF soldiers with SCI, MRSA, use of telehealth and MyHealtheVet and physical function/mobility (including issues of injury, overuse, and safety). These conditions cause significant morbidity and mortality in individuals with SCI/D and gaps exist between evidence-based recommendations and practice.

I.2 Significance and Consequences: Epidemiology, Morbidity/Mortality, QoL and Costs

Between 225,000 and 296,000 individuals in the US have some type of SCI/D that significantly affects life activities. The VA is responsible for the care of 22% of persons with SCI/D in the United States, making the VA the single largest source of care in this country for persons with SCI&D. While considered a highly heterogeneous population, persons with SCI&D face common obstacles and barriers following disability related to independent living. For example, between 50% and 75% of this population are unemployed. This is particularly significant because injury often occurs at a young age (almost 60% are $\leq$30 years old at onset of SCI/D).

The combination of long term survival and severe disability makes SCI/D among the most expensive of all medical conditions in VA (estimated at $26,735 per veteran per year; Yu et al. 2003). Estimated costs of care for SCI patients exceed $9 billion per year in the U.S., and over $1.5 million per patient lifetime. In the Nationwide Inpatient Sample maintained by the Agency for Healthcare Research and Quality, SCI resulted in the second highest charges in the U.S. and the third longest lengths of inpatient stay. Although the number of SCI/D cases is small, they account for a large and disproportionate share of costs.

The gravity of long term consequences of SCI/D is of particular importance given the special health care needs of the OEF/OIF veterans. SCI QUERI is conducting chart abstractions and surveying SCI providers to learn about unique needs and health care concerns of returning OEF/OIF soldiers with SCI.

Respiratory Health. Our implementation activities include work in preventive care for respiratory conditions. Respiratory complications are a leading cause of mortality after SCI (DeVivo et al., 1993; Minaire et al., 1983; Kiwerski, 1992; Smith et al., 2007) and the leading cause of death (22%) in persons who survived the first year after SCI (DeVivo et al., 1999). In one study, individuals with SCI/D who contracted influenza or pneumonia were 37 times more likely to die from illness complications than comparable individuals from the general population (DeVivo et al., 1993). Furthermore, pneumonia is a leading cause of death during all time periods, ranging from 18.9% during the first post-injury year to 12.7% after the first post-injury year through 30 years (Ragnarsson et al., 1995; DeVivo et al., 1993). VA SCI QUERI data have shown a 30-day mortality rate for those hospitalized with community-acquired pneumonia (CAP) of 8.5% (**Chang et al., 2005**) and cumulative mortality of 42.1% over a median follow up of 3 years (**Burns et al., 2004**). Recent data indicate that veterans with SCI who contract pneumonia or influenza are almost 10 times more likely to die compared to those with other acute respiratory infections (**Weaver et al., 2006**). Having pneumonia or influenza was also highly associated with increased hospital admissions compared to other respiratory infections (**Weaver et al., 2006**). Using a combination of patient, provider and system interventions, vaccinate rates improved from 26% and 25%, respectively for influenza and pneumonia in veterans with SCI/D age 65 and over, to 68% and 88% for influenza and pneumonia vaccines in FY2004 (veterans age 50+) (**Weaver et al. 2007**). QUERI's work has been sustained as vaccination rates continue to improve (EPRP FY08 through Q3 rates for SCI: influenza 80%; pneumonia 97%).

In addition to respiratory vaccinations and pneumonia, we are addressing issues related to tobacco use, chronic obstructive pulmonary disease (COPD), and sleep apnea. Studies of veterans with SCI/D have demonstrated that approximately 30%-33% still smoke (Spungen et al., 1995; OQP, 2006) compared to 21% in the general U.S. adult population. In a recent systematic review, Shamsuzzaman and colleagues, concluded that 20% of adults have at least mild obstructive sleep apnea (OSA) and 7% have at least moderate disease (Shamsuzzaman, Gersh & Somers, 2003). Estimates of prevalence of sleep-disordered breathing are significantly higher in the SCI/D population. Most studies that have used sensitive testing methods show a prevalence of sleep apnea syndrome (SAS) in the range of 30% to 62% in individuals with

tetraplegia (McEvoy et al., 1995; Stockhammer et al., 2002), and the elevated risk included individuals with motor-incomplete injuries (**Burns et al., 2001**).

Little is known about the prevalence of COPD in SCI/D, but given the impaired respiratory function and the significant number of veterans with SCI/D who smoke, it is likely to be common in this population. A review of the VA administrative databases for inpatient and outpatient care in FY04 found 1,658 veterans with SCI/D with a diagnosis of COPD, a number that represents approximately 13% of all veterans with SCI&D treated in VA that year.

Pressure Ulcers (PrUs). SCI is the most costly medical condition for veterans (~ $26,735 per person per year) and over half of all VA hospital stays for veterans with SCI are attributable to PrUs. The costs of caring for PrUs in veterans with SCI are substantial. In VA in FY 2005, 1,586 unique patients had 2,350 admissions for PrUs (about 1/3 of all VA SCI admissions; Bates-Jensen, **Guihan, Garber & Burns**, in press). The costs of PrU-related hospitalizations for the 150 patients enrolled in our previous study were nearly $9 million for FY 2003-2005. In a chart review conducted by **Garber** and Rintala (2003), they found that Stage IV pressure ulcers were the most prevalent as the worst ulcer documented.

In 1968 researchers found that 50% of veterans with tetraplegia and 30% of individuals with paraplegia required hospitalization for treatment of pressure ulcers (Krouskop, 1983). In the last three decades, there has been little change in the prevalence or incidence of PrUs among individuals with SCI/D. Epidemiological studies predict that 36-50% of all persons with SCI who develop pressure ulcers will develop recurrent sores within the first year after initial healing (Niazi, 1997; Salzberg et al, 1996) and that more than 50% of individuals with SCI will experience some tissue breakdown during their lifetime (**Goldstein, 1998**). Treatments including long term hospitalizations, surgical procedures, wound care products, and equipment necessitated by pressure ulcers account for more than 6.5 billion dollars each year in the U.S. (CDC, 1990; NIDRR, 1997).

Cardiovascular (including obesity). Individuals with SCI are believed to have accelerated and premature coronary heart disease. Model Systems' data shows that heart disease is the leading cause of mortality (35–46%) for patients surviving >30 years after SCI and among those over age 60 (DeVivo & Stover 1995; Whiteneck et al 1992). Cardiovascular disease (CVD) mortality rates in the SCI/D population are more than double the rates in the non-disabled population (Kocina, 1997). Respiratory and CVD conditions combined account for over half of all deaths in patients with SCI/D (DeVivo & Stover, 1995; Ragnarrson et al., 1995; Whiteneck et al., 1992; Zeilig et al 2000). Results from the National Center for Health Statistics' National Death Index (NDI) data, show that the most common underlying and contributing causes of

death for veterans with SCI/D (n=2,468; FY01-2) were heart disease (25%), malignant neoplasms (22%), accidents (9%) and chronic respiratory diseases (5%) (**Smith et al., 2007**).

Obesity. Changes in body composition (e.g., reduction in muscle mass), lowered metabolic rate, and limitations in physical activity that follow SCI contribute to weight gain. Available estimates from VA data indicate that around 65% of individuals with SCI can be classified as being overweight or obese (Gupta 2006, **Weaver et al. 2007**). It is important to note that these frequency estimates are based on Body Mass Index (BMI), an index of adiposity that has been shown to underestimate body fat in individuals with SCI (Jones, 2003). In the general population, obesity has been acknowledged as a risk factor for the development of a wide range of metabolic complications including glucose intolerance, insulin resistance, diabetes mellitus (DM), coronary and cardiovascular risk factors such as hypertension (HTN) and dyslipidemia. These metabolic conditions are even more frequent in individuals with SCI compared to the general population and are also major causes of morbidity and mortality in individuals with SCI (Duckworth et al, 1980; Bauman et al., 1999; Bauman and Spungen, 1994; Demirel et al., 2001). In SCI, increased cardiovascular risk factors such as hypertension and diabetes mellitus have been linked to obesity (**Weaver et al. 2006; Rajan-unpublished**). Case reports suggest that the obesity in persons with SCI/D may contribute to additional burden in SCI such as poor functional outcome, impaired mobility, longer hospital stays and need for expensive special equipment (Blackmer and Marshall, 1997). Individuals with SCI/D present with a number of illnesses and complications related to their condition that may be affected by their obesity.

Pain and Depression. Pain and depression have serious negative impacts on functioning among individuals with SCI/D. Pain is common enough after SCI to be considered an expected condition. Moreover, pain is severe and/or disabling in 20% to 40% of persons with SCI who have pain (Jensen, et al., 2005). Especially concerning is the fact that pain conditions among persons with SCI tend to be stable over time, in spite of active treatments. In fact, changes in a pain condition that do occur over time after SCI are likely to assume a worsening course (Rintala, et al., 2004).

Depression also is a serious problem for veterans with SCI/D. Estimates of prevalence rates for depression during the first year of SCI/D range up to 40% and persons with SCI may be five times as likely to experience depression as persons in the general population (Boekamp et al., 1996). Depression in persons with SCI/D results in increased risks of suicide, secondary complications such as pressure ulcers, and increased utilization of health care services (Consortium for Spinal Cord Medicine, 1998).

Unfortunately, the co-occurrence of pain and depression is more common than either condition alone (Cairns, et al., 1996). This is of particular concern because pain and depression levels tend to be more severe when co-occurring (Campbell et al., 2003), and the presence of one condition adversely effects the detection and treatment of the other condition (Banks & Kerns, 1996).

Physical function/mobility. Musculoskeletal problems are common following SCI/D. Although the initial spinal cord injury is serious and usually permanent, persons with SCI/D are at increased risk for further physical/mobility impairment due to overuse (e.g., upper extremity weight-bearing to perform wheelchair propulsion and transfers), awkward postures (e.g., frequent reaching overhead from a wheelchair or transferring from the floor to a wheelchair), injuries (due to falls, poor wheelchair and transfer skills) and aging. Patients with SCI have severe loss of bone mass, predominantly in the lower extremities (Biering-Sorensen et al., 1988; Garland et al., 1992; Comarr et al., 1962; Ragnarsson and Sell, 1981). There is rapid bone loss below the level of neurologic injury in the first several months following acute SCI. A new steady state between bone reabsorption and formation is reestablished about 2 years after SCI (Jiang et al., 2006). In 2006, in a sample of 8,849 veterans with traumatic injuries, 5.15% were identified as having any extra spinal fracture as documented by ICD-9 codes. The majority of these (85.5%) were lower extremity fractures (SCI QUERI unpublished data, 2007). Another area of concern is that of upper limb pain and injury which is very common in SCI/D. These problems have received more attention recently as the life expectancy of individuals with SCI approaches that of the general population. Most studies investigating the prevalence of upper limb pain and injury have focused on carpal tunnel syndrome and rotator cuff disease.

The wheelchair is among the most common and important of rehabilitation devices following SCI/D, particularly for persons with mobility impairments (Jones & Sanford, 1996). Despite advances in wheelchair technology, users continue to face significant limitations to mobility and increased risk associated with wheelchair tips, falls, and fall-related injuries. Wheelchair falls are a high-risk, high volume, high-cost problem for persons with SCI/D.

I.3 Treatment/Management Evidence Base

Evidence-based clinical practice guidelines (CPGs) specific to SCI/D have been developed for pressure ulcer prevention and management, upper limb preservation of function, bowel management, deep vein thrombosis (DVT), bladder management, acute respiratory management, depression, and autonomic dysreflexia by the Consortium for Spinal Cord Medicine Consortium (CSCM) supported by the Paralyzed Veterans of America (PVA). The

Consortium is made up of 21 health professional and payer organizations representing physicians, therapists, nurses, psychologists, social workers, consumers, insurance case managers and policy makers from VA, public and private health care sectors. The Consortium develops, produces, and disseminates evidence-based CPGs and companion consumer guides. The CPGs are based on a combination of empirical evidence and expert consensus. We continue to use the guidelines and identify best practices to implement and to determine how best to guide and assess our implementation efforts. For example, we were funded to identify strategies to help providers implement the Upper Extremity CPG (Project Label: Upper extremity GAPs). Numerous elements of the pressure ulcer guideline are being used in a multicenter collaborative to improve patient self-management (Label: Pressure ulcer self-management), to standardize certain aspects of pressure ulcer management in SCI (Project Label: PUSH Tool) and to create a disease management protocol for pressure ulcer management using VA's telehealth program (Project Label: Teleheallth for PrU). The CSCM CPG for depression following SCI is the focus of a number of projects. Specifically, SCI QUERI has had a central role in two SCI/D Services educational programs focused on the depression CPG. RRP funding is being used for a project that coordinates the implementation of the CSCM CPG for depression between hub and spoke facilities in VISN 6.

We also continue to review and apply evidence available from the general population when appropriate. This was the case for our influenza and pneumococcal pneumonia vaccine work. Studies of vaccine effectiveness and of strategies to improve vaccination rates had not been conducted with SCI/D participants prior to our vaccine implementation work. However, given the high rate of respiratory morbidity and mortality in SCI/D, and knowledge that vaccination rates were low in veterans with SCI/D, we developed a national implementation project to improve vaccination rates in SCI/D. The evidence in this case was well-accepted by the SCI/D community (**Evans et al., 2003; Weaver et al, 2003; Weaver et al., 2007**). We have since identified several other areas where we have undergone similar thinking. These include tobacco use cessation, pain management, and use of mechanical insufflation/exsufflation for clearing respiratory secretions in persons with higher level injuries.

Below we briefly describe the evidence base for each area of focus.

Respiratory Health

Tobacco Use and Cessation. Smoking tobacco remains an important modifiable cause of premature death in the US. Smoking results in approximately 420,000 deaths annually (http://odphp.osophs.dhhs.gov/pubs/guidecps/text/CH54.txt). Studies have consistently linked tobacco use with a number of chronic diseases including pulmonary and cardiovascular

conditions, both of which are at increased incidence in SCI/D. The evidence-based guidelines for tobacco cessation (vaww.oqp.med.va.gov) indicate that a brief tobacco intervention is effective and every patient should be offered at least one of these treatments. Treatments include counseling (individual, group or telephone), behavioral therapy and pharmacotherapy including nicotine gum, nicotine patch, and bupropion. The Public Health Service and VA CPGs recommend that tobacco users who are willing to make a quit attempt should receive both counseling and pharmacotherapy (Dept of Health and Human Services, Nov. 2000). The recommendation includes use of the 5 A's: ask (about tobacco use), advise (to quit) assess (willingness to quit), assist (in quit attempt), arrange (for treatment, follow-up).

Community Acquired Pneumonia (CAP). Although CPGs to address CAP exist, there is controversy regarding whether to treat CAP empirically or based on specific pathogen identification. The American Thoracic Society suggests an empiric approach (Niederman et al., 1993; 2001), while the Infectious Disease Society of America promotes use of diagnostic tests in determining etiology and treating appropriately (Bartlett et al., 1998; 2000). Neither of these guidelines specifically addresses treatment of CAP in persons with SCI/D. VA utilizes the five Joint Commission on Accreditation of Healthcare Organizations (JCAHO) measures to monitor quality of care for CAP. These include: oxygenation assessment within 24 hours of arrival, documentation of pneumonia and influenza vaccinations prior to discharge (for CAP), blood cultures obtained prior to the start of antibiotics, tobacco cessation for smokers admitted for CAP, and start of antibiotics within 8 hours of arrival at the hospital (http://vaww.oqp.med.va.gov/).

Sleep Apnea Syndromes (SAS). Several groups have published guidelines for diagnosis and management of sleep disordered breathing (Chesson et al., 1997; ISCI, 2003). The recommendations are similar and include: 1) performing a general evaluation of sleep problems as part of the clinical history and physical examination; 2) obtaining bed partner observations of snoring, breathing pauses, choking or gasping, restless sleep and excessive daytime sleepiness; and 3) considering other risk factors including male gender, obesity (BMI$\geq$30 kg/m^2), large neck circumference (>16.5 inches in men) and hypertension. For most patients, a full-night polysomnography is recommended for diagnosis, but for patients who are in the high-risk group (i.e., habitual snoring, excessive daytime sleepiness, BMI > 35 kg/m^2 and observed apneas), a cardio-respiratory sleep study may be an acceptable alternative. The cardio-respiratory sleep study requires a minimum of four channels: respiratory effort, air flow, arterial oxygen saturation, and ECG or heart rate (Chesson et al., 1997). If it is determined that the patient has sleep apnea, treatment may include lifestyle changes (e.g., weight loss, reduced

alcohol consumption before bed, body position – lateral vs. supine), oral appliances, positive airway pressure devices, or surgical intervention (ICSI, 2003).

Chronic Obstructive Pulmonary Disease (COPD). It has been established that persons with higher-level SCI/D have reduced vital capacity and are at increased risk of respiratory symptoms (Linn et al., 2003). Furthermore, individuals with SCI/D who also smoke are at excessive risk for obstructive lung diseases. The VA/DOD practice guidelines for management of COPD are available at http://www.oqp.med.va.gov/cpg/cpg.htm. The guidelines include diagnosis of COPD using spirometry, providing education and encouraging smoking cessation, provision of influenza and pneumococcal pneumonia vaccinations, and treatment of COPD exacerbation using pharmacotherapy, and when indicated, antibiotics. The goal is to gain and maintain control over the symptoms of COPD which include cough, sputum production and dyspnea on exertion (pocket guide to COPD diagnosis, management and prevention, July 2005).

Cardiovascular and Metabolic Health (primary focus: obesity)

Sedentary lifestyle, weight gain, and metabolic changes place persons with SCI/D at high risk for atherosclerotic heart disease (Szlachcic et al., 2001), including ischemic heart disease and acute myocardial infarction. It is particularly important that evidence-based guidelines for primary and secondary prevention are applied to individuals with SCI/D. One of the difficulties in identifying and treating heart disease in the SCI/D population is that persons with SCI/D often have atypical presentation because they may not perceive cardiac pain with higher-level injuries. Although screening for cardiac disease in SCI/D remains controversial, closer surveillance and routine diagnostic testing have been advocated by many SCI clinicians.

Obesity. Guidelines put forth by VA and the National Heart, Lung, and Blood Institute (NHLBI) for the identification, evaluation and treatment of overweight and obesity in adults are available for use in “able-bodied” individuals. A combination of diet, exercise and behavioral modification remain the choice of treatment for overweight and obesity in the general population (NHLBI guidelines). There is a paucity of data on weight loss interventions that have taken into account the unique nutritional needs and low to limited activity patterns of individuals with SCI. Studies identifying strategies specifically targeting individuals with SCI are only recently emerging (Chen, 2006).

Cardiovascular disease (CVD) risk factors: CPGs endorsed by VHA's National CPG Council are available for the management of dyslipidemia and hypertension (HTN). In the case of hyperlipidemia (http://www.oqp.med.va.gov), VA evidence-based guidelines for lipid screening and management include specific interventions for individuals with HDL < 40 mg/dl, total

cholesterol ≥ 200 mg/dl and/or triglycerides ≥ 400 mg/dl. Although common, little empirical information is available about HTN in persons with SCI/D. Studies in able-bodied individuals have established associations between HTN, obesity, hyperinsulinemia, and disorders of glucose tolerance. Although an increased prevalence of HTN has been reported in persons with SCI/D, little is known about these associations in the SCI/D population (Yekutiel et al., 1989). A recent review of clinical data on a cohort veterans with SCI/D suggests that 22% have high BP (≥140/90 mmHg), and those who were overweight or obese, black, older (age 50+), and paraplegic were more likely to have higher blood pressure (**Weaver et al. 2006**).

Pressure Ulcers

The CSCM published a CPG in 2001 that addressed pressure ulcer prevention and treatment for SCI. Pressure ulcer risk assessment and prevention efforts in all populations emphasize a comprehensive approach including skin assessment and evaluation of factors most commonly reported to be associated with pressure ulcer development. Research, expert opinion and CPGs stress that numerous factors and prevention techniques such as patient education, pressure reduction, hygiene, nutrition, environmental protection, and psychosocial support yield the greatest gains in pressure ulcer prevention. We are committed to using the CSCM CPG and evidence from other populations as the basis of our implementation efforts in this area. As new evidence becomes available, we will also incorporate it into our implementation efforts.

Pain and depression

Interdisciplinary intervention is consistently recommended as the best approach to treating SCI/D pain (Bryce et al., 2000; Finnerup, et al., 2002; Siddall and Middleton, 2005). In fact, the Rehabilitation Accreditation Commission (2002) specifies that an interdisciplinary approach is preferred in all aspects of rehabilitation care. In numerous medical populations, interdisciplinary treatments for pain have proven to be superior to single-discipline care across many studies (Flor et al., 1992).

The SCI CPG for depression management was published in 1998. It recommends interdisciplinary care in order to address the complicated interplay of biological, psychological, and social factors important to depression among persons with SCI. According to the SCI depression CPG, treatment plans should be developed and coordinated by an interdisciplinary team of SCI specialists utilizing various modalities including psychotherapy, social work interventions, and psychopharmacological agents.

Physical function/mobility

One of the more recent CPGs published by the CSMC was on the preservation of upper limb function following spinal cord injury. However, similar guidelines regarding fracture management and wheelchair use/safety are lacking. Current work by one of our executive committee members, A. Nelson, involves development of a wheelchair training program to reduce falls and injuries from use of wheelchairs in SCI/D. Additionally, members of the QUERI executive committee (Burns, Hoenig), QUERI leadership (Weaver) and others are examining issues related to fracture management in SCI as a first step toward implementation.

I.4 Current Practices and Quality/Outcome Gaps

Systematic reviews have demonstrated that people with severe disabilities receive substandard preventive services and chronic disease management as compared with national recommendations (e.g., Healthy People 2020) and the general population. For example, disability among Medicare patients was an independent risk factor for not receiving preventive care services. Despite repeated computerized reminders, respiratory vaccination rates remained low for chronically ill Medicare patients who saw neurologists and physiatrists. Adults with physical, mental, and developmental disabilities receive fewer services from primary care physicians and specialists, fewer prescriptions, and less assistive equipment (Chan et al., 1999, 2002).

Despite well-defined evidence-based CPGs, SCI QUERI and the SCI/D Services have identified areas where gaps remain in provision of recommended care for patients with SCI/D (External Peer Review Program (EPRP), FY1996-2007). The following discussion reviews gaps between evidence based care and practice for the conditions discussed in Section I.3.

Respiratory Health

Tobacco use and cessation. Smoking is an important modifiable cause of premature death, responsible annually for an estimated 6 million years of potential life lost. Although VA Tobacco Cessation Guidelines and performance measures exist, counseling to discontinue tobacco use was initially low in veterans with SCI/D (56% vs. 74% in general veteran population; EPRP, FY2003), but now is very high (98% in FY06). Despite this improvement, the percentage of smokers has not changed much (32% in FY04-06, 30% in FY07 & FY08) in the last several years. VA performance measures (FY08) suggest that most smokers were offered medications/NRT or referred to counseling (84% and 94%, respectively). These data suggest that this may not be sufficient to address smoking in SCI. Efforts to decrease tobacco use in

SCI/D may require combined strategies and techniques such as motivational interviewing (Project Label: Smoking cessation).

CAP. Recent work by SCI QUERI showed that outpatient visits for pneumonia account for nearly 30% of all respiratory visits to the VA by veterans with SCI, and the rate of pneumonia visits is more than twice that of the general veteran population (**Smith et al., 2007;** Lee, 2002). Our preliminary work suggests that patients are not always receiving guideline recommended care (**Burns et al. 2004; Chang et al., 2005**). In a pilot study, we found that sputum gram stains and cultures were obtained for 39% of persons admitted with CAP, while only 12% had a causative agent identified (**Burns et al., 2004**). These data suggest that care processes could be improved to manage CAP in SCI/D.

SAS. Sleep-disordered breathing is highly prevalent in the SCI/D population. Studies using sensitive testing methods show a prevalence of SAS of 30% or greater in persons with tetraplegia (McEvoy et al., 1995; Stockhammer et al., 2002). Data from one study found 14.9% of tetraplegic and 3.7% of paraplegic patients with diagnosis of sleep apnea, and only 47% of the diagnosed patients received treatment (Burns et al., 2001). It is likely that untreated sleep apnea is also a risk factor for other cardiovascular diseases in this population, as is the case for the general population (Guidry et al., 2001; Nieto et al., 2000), and may put this population at greater risk for other common complications of SCI/D, such as development of pressure ulcers and depression. The recommended treatment for sleep apnea is Continuous Positive Airway Pressure (CPAP). However, CPAP adherence appears to be particularly low in persons with SCI/D. Many persons with SCI/D are unable to reposition the mask independently due to impaired hand function (Burns et al., 2001).

COPD. We currently have little information about diagnosis and management of COPD in SCI. We suspect that use of bronchodilators may be underutilized in this population. Our current study will examine whether gaps in care exist for SCI/D (Project Label: Gap).

<u>Cardiovascular (and obesity)</u>

Hyperlipidemia. Although complete lipid profiles are frequently obtained during annual evaluations for persons with SCI/D, little is known about the management of lipids in this population. In FY 2002, EPRP data indicated that only 21% of SCI/D patients with hyperlipidemia were prescribed lipid-lowering medication. More recent data indicate that 53% of veterans with SCI/D have LDL values under 100 mg/dl (FY04), suggesting that almost half of the SCI/D population would benefit from improved LDL control.

Obesity. Despite obesity being a common problem in individuals with SCI/D, the clinical assessment and sequelae of obesity are not well understood. Practical guidelines and

measures to monitor obesity in the clinical setting are lacking. One of the first steps in the evaluation of obesity is the application of BMI and the use of waist circumference (WC) measurement (NHLBI guidelines) to the SCI/D population. While specific cut-points are available for "able-bodied" persons, the use of these values to classify people with SCI/D as overweight and obese is limited by the unique body composition changes that follow SCI/D. Also, the association between obesity and health consequences has not been adequately addressed in this population.

HTN. Data from the Diabetes QUERI indicate that approximately 22% of the SCI/D cohort had a blood pressure reading >140/90 in FY00-01 (**Weaver et al, 2006**). Yet, EPRP data (2002) indicate that less than 50% of people with HTN and SCI/D take antihypertensive medications. More recent EPRP data suggest that approximately 30% of veterans with SCI/D have blood pressure values greater than 140/90.

DM. Analysis of EPRP chart review data from FY 2002 to 2004 by SCI QUERI showed significant improvements in the patient care process and intermediate outcome measures. Between FY 2002-2004, the proportion of cases who received testing for HgA1c (89% to 93%), lipids (88% to 96%), and retinal exams (55% to 71%) increased significantly. Significant improvements in intermediate clinical outcome measures also were noted in the proportion of veterans with HbA1c levels ≤ 9% ($p<0.001$) and those with poorly controlled levels ($p=0.022$; **Rajan et al., 2008**). We anticipate these improvements will continue as DM was made a performance measure for SCI providers in FY 2005. In fact, our most recent review in FY07 of diabetes measures for SCI providers found that performance levels were met or exceeded in every area except retinal exams (which were close to target).

Pressure ulcers

The prevalence and incidence of pressure ulcers in the SCI/D population are remarkably high, and unfortunately, have not changed much during the past several decades. A 1968 study found that 50% of individuals with tetraplegia and 30% of individuals with paraplegia required hospitalization for treatment of pressure ulcers (Krouskop et al., 1983) and recent studies show little change. 36-50% of all persons with SCI/D who develop pressure ulcers will develop recurrent ulcers within the first year after initial healing (Nizai et al., 1997; Salzberg et al., 1996), and > 50% of individuals with long-term SCI/D experience some tissue breakdown in their lifetime (Goldstein, 1998). In the VA SCI/D population, pressure ulcers account for significant hospital days and costs (**Guihan et al., 2007**). In the most recent study of pressure ulcers in veterans, **Guihan et al. (2007)** found that 40% of those with a healed stage II/IV pressure ulcer experienced a recurrence within 4.5 months.

Pain and depression

SCI QUERI work has determined that approximately 22% of veterans with SCI/D had at least one encounter with a healthcare provider with a diagnosis of depression (**Smith et al., 2007**). Of those diagnosed, 72% received an antidepressant prescription. However, a large percentage (67%) did not continue antidepressant use for at least six months, as recommended in the CSCM CPG for depression.

I.5 Significant Influences on Current Practices and Outcomes

There are several major sources of influence on current practices and outcomes for patients and providers in the SCI/D System of Care. SCI/D Services serves as a proactive partner in QUERI. SCI/D Services sets many of the policies for care provision in VA SCI centers, and closely monitors the field for current practices and gaps in care. They work closely with the VA Office of Quality and Performance (OQP) to define performance measures for SCI and uses EPRP data to assess preventive, primary, and specialty care (e.g., the impact of our efforts to improve vaccination rates). Implementation of performance measures has had a great impact on care processes and outcomes in the SCI/D population. In addition to the existing SCI/D performance measures for influenza vaccination, pneumococcal vaccination, and smoking, as of FY05, performance measures were added for diabetes management. These include glycosylated hemoglobin levels, lipid screening, blood pressure measurement, and periodic eye exams. SCI QUERI and the SCI/D Services continue to work together to identify areas of need. For FY07, additional measures for smoking cessation that address the 5 A's (ask, advise, assess, assist, arrange) were added. New in FY08 are measures related to pressure ulcer development and treatment planning.

Communication with clinicians throughout the SCI/D System of Care has a significant influence on practice, as we experienced directly in our respiratory vaccination project (**Weaver et al., 2007**). A quarterly newsletter (SCI/D Services Newsletter) facilitates dissemination of information and announces periodic discussion groups on e-mail, and a monthly leadership call brings clinicians, administrators and QUERI representatives together regularly.

SCI QUERI is fortunate to have several strong advocacy groups that are supportive of our work. Veteran service organizations for SCI, including the PVA, have supported many clinical activities, research activities, and the development of CPGs (the latter through the CSCM). United Spinal Association (USA) has supported research conferences and pilot funding for research in SCI. Specifically, USA has awarded research funding to QUERI staff and executive committee members and has supported SCI QUERI's attendance at the annual America

Congress on Spinal Cord meetings where study results are disseminated to the field. Most recently, they supported the Pressure Ulcer Collaborative meeting held by SCI/D Services in Seattle, WA in October, 2006. A follow-up meeting was held in August 2008.

In the past year, SCI QUERI has engaged in activities with VHA's MyHealth*e*Vet (MHV) program, the VA Office of Care Coordination, VA's Employee Education Service (EES) and VA National Center for Health Promotion and Disease Prevention (NCP). These efforts are designed to increase dissemination of evidence-based findings to patients and providers. MHV is developing an SCI/D condition specific center on their web portal. SCI QUERI has partnered with EES and SCI/D Services to develop CPG-consistent training presentations for VA SCI practitioners, and to empirically examine methods for enhancing SCI/D Services educational programs (project label: SCI-D: CPG). Working with the Office of Care Coordination, SCI QUERI is developing and testing a disease management protocol for pressure ulcer prevention for the telehealth program. In conjunction with NCP, SCI QUERI is developing weight management materials for veterans with SCI who are participating in the VA's Managing Obesity in Veterans Everywhere (MOVE!) Program.

Finally, the Model Spinal Cord Injury System program, sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services, US Dept of Education, provides assistance to establish innovative projects for the delivery, demonstration, and evaluation of comprehensive medical, vocational, and other rehabilitation services to meet the needs of individuals with SCI. Many of their findings serve as the basis for SCI QUERI research. Dr. Arthur Sherwood, Science and Technology Advisor at NIDRR, is a member of our executive committee. We are working with the SCI Model System program in Seattle to obtain their expertise in addressing behavior change strategies for persons with SCI in a number of areas.

I.6 SCI QUERI Center Goals

SCI QUERI's long-term goals are to support, promote, and maintain the health, independence, functioning, quality of life, and productivity of veterans with SCI/D throughout their lives. Our interim goals are to develop and implement evidence-based interventions that: 1) improve secondary prevention and treatment for chronic comorbid conditions, 2) increase patient self-management and satisfaction by promoting an informed, empowered patient, and 3) further develop a system of care that results in a prepared, proactive interdisciplinary healthcare team. We also maintain a long-term goal of developing new investigators that will help us extend our evidence base to the care of persons with SCI/D.

Our first priority was to reduce respiratory complications in persons with SCI/D through efforts to increase respiratory vaccinations. Our current implementation efforts are directed at increased delivery of tobacco use cessation care to veterans with SCI/D who smoke. Another implementation project focuses on the development of strategies, such as telehealth, to improve management of pain and depression. We continue to address ways to improve pressure ulcer assessment, management and prevention through several efforts including a collaborative effort with VA SCI centers to improve pressure ulcer assessment management (supported by USA and SCI/D Services) and the development of a disease management program for telehealth (Guihan & Ho, SCI executive committee member). Dr. Guihan is also collaborating with Dr. Barbara Bates-Jensen, an expert in wound care in the geriatric population to examine the efficacy of a device to identify skin problems in persons with SCI before they can be identified using visual inspection techniques (Project Label: Pressure ulcer assessment 1).

Successful management of obesity involves both accurate assessment and treatment. SCI QUERI has several current and planned projects in the area of obesity, all with the long-term goal to implement a weight loss/weight maintenance program for veterans with SCI/D (label: MOVE! SCI). Our work in the area of obesity includes a three year grant from VA Rehabilitation Research & Development (RR&D) to identify and evaluate simple, practical, inexpensive bedside techniques that can be used by clinicians in all VA settings to determine overweight and obesity status in individuals with SCI (Goldstein & Rajan; Project Label: Obesity assessment and impact). This study will also study the impact of obesity on health conditions, function and quality of life. Results of this study could have significant impact on the way SCI patients are screened for and/or diagnosed with obesity, which could ultimately lead to better targeting of prevention efforts. Drs. Rajan and Goldstein have also received funding to develop and/or adapt weight management materials for veterans with SCI who are participating in the VA's Managing Obesity in Veterans Everywhere (MOVE!) program. This work is being done in collaboration with the VA National Center for Health Promotion and Disease Prevention, developers of the *MOVE!* program. A related project, funded by QUERI core, is examining behaviors related to diet and exercise in individuals with SCI.

I.7 Plans for Achieving QUERI Center Goals

We have planned several implementation projects in the next few years. A grant to address smoking cessation in SCI is planned for June 2009 (QUERI steps 4, 5) (Project Label: Smoking cessation). Concept papers for SDPs are being developed to telehealth behavioral interventions for pain and depression in veterans with SCI/D. We are working more with our

executive committee on projects that they have developed and are involving them more on QUERI projects to expand our efforts. Specifically, Dr. Audrey Nelson recently submitted a request to extend her HSR&D funded study on pressure ulcer assessment to implement the tool in SCI centers (Project Label: Pressure ulcer assessment).

In all of our projects, each designed to reach our stated goals, we seek advice from our partners. This means that we consult with patients through focus groups, interviews and surveys, align with the needs of the SCI/D Services, involve our external stakeholders in PVA and USA, regularly consult with our executive committee through monthly conference calls, and work closely with practitioners and administrators in the SCI Centers, primary care teams and clinics. We also seek information from and respond to VA OQP and other VHA offices support systems. (See the Wiring Diagram).

1.8 Spinal Cord Injury QUERI Implementation Science Goals

SCI QUERI implementation activities are informed by the Promoting Action on Research Implementation in Health Services (PARIHS) framework. The SCI QUERI group uses the framework to guide the development and conduct of projects through the steps of the VA QUERI process. The implementation science goals of SCI QUERI are aimed at: 1) empirically testing the framework and 2) applying the framework to implementation studies. Specific implementation science goals are shown in the table below. The group recognizes that these are ambitious goals that will be achieved over multiple projects and years. One way that the group will monitor these goals is through a newly created implementation science team within SCI QUERI.

The SCI QUERI implementation science (IS) team is comprised of Drs. Ullrich, Guihan, and VanDeusen Lukas (Executive Committee Member). The IS team meets with the leaders of each major research area of SCI QUERI to discuss the research in each area and to develop plans for addressing implementation science goals. The IS team meets quarterly to discuss progress towards IS goals (e.g., identification of common themes, lessons learned, routine assessment of measures, etc.) across studies and schedules additional meetings to address particular issues. The team has developed a follow-up schedule to assess the extent to which each projects meets its IS goals and/or any needed modification of those goals.

The PARIHS framework posits that successful implementation is a function of three elements: evidence, context and facilitation. Evidence includes research findings, clinician experience and patient experience. Context comprises culture, leadership and evaluation. Facilitation, defined as techniques by which one person makes things easier for others, includes

specific purposes, roles and skills, and attributes. SCI QUERI projects have addressed goals in each element of the framework.

Spinal Cord Injury QUERI Implementation Science Goals
EVIDENCE
Goal 1 Develop a stronger evidence base to support implementation. **Goal 1a)** Develop research evidence. **Goal 1b)** Develop evidence in terms of clinician experiences. **Goal 1c)** Develop evidence in terms of patient experiences. **Goal 1d)** Synthesize research evidence, clinician experiences, and patient experiences.
Goal 2 Develop methods and instruments for measuring types of evidence (research, clinical, patient) that are important to implementation.
Goal 3 Increase understanding of the impact of various types of evidence (research, clinical, patient) on practice within the SCI system of care.
Goal 4 Increase providers' knowledge of evidence bases (research, clinical, patient).
CONTEXT
Goal 5 Develop better methods and tools for measuring contextual factors important to implementation (culture, leadership, evaluation).
Goal 6 Develop and evaluate methods and tools to influence contextual factors that support implementation.
Goal 7 Understand associations between contextual factors and variation in implementation of evidence-based care.
FACILITATION
Goal 8 Develop and evaluate methods and instruments for measuring aspects of facilitation.
Goal 9 Develop and evaluate methods and tools to facilitate adoption of evidence-based practices into SCI system of care.

Projects Addressing "Evidence" goals

The implementation science goals of SCI QUERI are addressed in projects across the various clinical research areas (e.g., respiratory, obesity, pressure ulcer, pain and depression). Focus groups and key informant interviews are utilized to understand how stakeholder (e.g.,

clinician, patient, and caregivers) experiences impact on healthcare practices. Examples include:

- Studies of patient and provider views of clinical practice guidelines (Project Label: Upper Extremity GAPs).
- The project to increase influenza and pneumococcal vaccination rates which included targeting (or changing) patients' and providers' behavior as part of a complex set of interventions (Project Label: VIP).
- Developing and testing a disease management protocol to use telehealth to improve patient self-management skills in order to prevent pressure ulcers (Project Label: Pressure Ulcer Chronic Disease Self-management).

SCI QUERI is also active in developing, synthesizing and disseminating evidence for practice in the SCI/D system of care. For example, expert panels were used to synthesize research evidence with clinician experience in the development of a pressure ulcer assessment tool (Project Label: PUSH Tool) and in a planned project adapting MOVE! materials for veterans with SCI (Project Label: Adapting MOVE! Materials). Other examples include:

- Study to develop a tool for the identification and management of obesity (Project Label: Obesity assessment and impact)
- Testing a method for detecting pressure ulcer development (Project Label: Pressure Ulcer Assessment).
- Educating providers about the CPG for depression after SCI (Project Label: SCI-D: CPG).

Projects Addressing "Context" goals

SCI QUERI also works to understand and influence contextual factors important to implementation. Examples include:

- Upper Extremity GAP project examining how organizational factors are associated with use of the CPG for upper extremity function (Project Label: Upper Extremity GAPs).
- Development of a tool assessing elements of the PARIHS model (Project Label: SCI-D: CPG).
- Assessing provider satisfaction and barriers/facilitators between "Hubs" and "Spokes" in managing community-dwelling patients using telehealth to prevent pressure ulcers (Project Label: Telehealth for PrU).

Projects Addressing "Facilitation" goals

SCI QUERI has projects completed, underway or in planning to develop methods for facilitating the adoption of evidence-based practice. For example, the SCI–D: Hub-Spokes project involves the development of a facilitation strategy in partnership with clinicians and VISN-level leadership. Drs. Wallace and Guihan were co-authors of a paper on the use of facilitation in VA projects and Dr. Wallace was primary author of a paper on formative evaluation (based on the implementation project to improve influenza and pneumococcal vaccination rates).

Projects Addressing Multiple Goals

The implementation project to improve influenza and pneumococcal vaccination rates in veterans with SCI/D is an example of a project with a complex set of 4 interventions; the project was designed to address multiple factors within the PARIHS model that predict success of implementation. The project included structured formative evaluations, facilitation to address barriers, interventions for patients and providers, and interventions to address the health care system (Project Label: VIP; PI – Weaver). SCI QUERI has examined how different elements of the PARIHS model (e.g., leadership and clinician-level of evidence) may interact to predict the success of implementation interventions (PI – Burns).

Dr. Ullrich is active in a number of cross-QUERI projects that address multiple implementation science goals. He is participating with QUERI consultant Dr. Cheryl Stetler and other QUERI IRCs to develop an international collaboration with the PARIHS developers. The aim of this collaboration is to enhance our understanding of the framework, and how it might be appropriately applied and tested within an implementation research project. Additionally, it is hoped that the collaboration will allow for early access to tools and protocols developed by the PARiHS originators. Also, Dr. Ullrich is working with Dr. Stetler and other IRCs on a project to investigate the PARIHS framework in terms of research literature within and outside QUERI, and to directly investigate QUERI experiences with PARiHS.

Part II. Management Plan

II.1 Overview of Management Plan

This section provides information on our overall management plan for FY09. We have developed strategies to leverage funds with QUERI core dollars. We recently completed an HSR&D SDR on respiratory complications (Weaver & Goldstein), and a QUERI-related Nursing Research Initiative project (Thomason). We have an ongoing RR&D grant on obesity measurement (Rajan & Goldstein), support from the VHA Public Health SHG for a health care worker vaccine effort, support from PVA for a fellowship (Evans) and an education grant (Klebine & Weaver), several HSR&D funded rapid response projects and locally initiated projects (LIP) or core projects. We are also focused on continuing to obtain non-VA funding for our work. In the past, we have received funding through the Christopher Reeve Paralysis Foundation, the APS Seed Grant Program, the Seattle VA Epidemiologic Research and Information Center (ERIC) small grants program, and the Research Foundation for Prevention of Complications Associated with Healthcare. We will continue to use these programs as a source of funding. Leveraging funds is necessary in order to allow us to not only fund our own Core LIP projects, but support the day-to-day activities of SCI QUERI.

II.2 Staff and Executive Committee Roster

The following roster lists leadership, Executive Committee members, important core project staff (based at the Center's primary locations) and important off-site investigators. The Research Coordinating Center comprises the majority of the staff for SCI QUERI, including the Research Coordinator, Research Administrative Coordinator, and several other key staff. The Clinical Coordinating Center includes the two Clinical Co-Chairs, the Implementation Research Coordinator, the Clinical Administrative Coordinator, and 1 staff person.

Staff and Executive Committee Roster

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